

The Michigan FAS Web



*"When spider webs unite they can tie up a lion."
~African Proverb~*

BUILDING FASD STATE SYSTEMS

By Cheryl Lauber, RN, DPA

Cheryl Lauber is the Project Manager of the Michigan Department of Community Health's (MDCH) Fetal Alcohol Syndrome Program. While Cheryl has been involved with the State's FAS project for less than a year, she has extensive experience working with maternal and child health issues. Cheryl is a Family Nurse Practitioner by training and holds a doctorate in public administration. She has been with MDCH since 1990 and in addition to her somewhat new responsibilities with the FAS program, Cheryl is a consultant for many infant health programs with the State. She provides consultation to sudden infant death syndrome (SIDS) programs, fetal infant mortality review (FIMR) projects, Healthy Start programs, teen health centers and many other projects needing clinical expertise.

The goal of the fetal alcohol syndrome (FAS) program at MDCH is to reduce the number of children born in Michigan with FAS, to provide timely diagnosis, and to assist those diagnosed with needed support services. Services are provided through: 1) five multidisciplinary teams that diagnose and provide initial care planning, 2) community outreach and education projects at eleven local sites, and 3) training and consultation.

To contact Cheryl, call (517) 335-9483 or email lauberc@michigan.gov

This spring the FASD (Fetal Alcohol Spectrum Disorders) Center for Excellence hosted the first national meeting of state FAS coordinators. This groundbreaking meeting, "Building FASD State Systems," brought people together from all 50 states and Puerto Rico, with the common goal of improving FASD prevention and treatment services. The proceedings offered a good mix of information from experts in the field, sharing from state level program people and wonderful advice from parents and caregivers. Barbara Wybrecht, Carolyn Morado and I attended as representatives from Michigan.

The descriptions of model programs was probably the most helpful part of the agenda for me as I am new to the FAS community. The FAS coordinators from Kansas shared strategies for training including suggestions for curricula content. Several presentations highlighted the need to provide prevention strategies to more selective and indicated populations; that is women of child-bearing age who drink or are at risk for drinking during pregnancy, women with alcohol and drug problems, and women who have given birth to a child with FASD. The need for

basic surveillance and collection of demographics was also emphasized. This is a basic public health need that should become part of our systems-building efforts here in Michigan. The experiences from Minnesota clearly set the gold standard for statewide systems.

I was grateful to hear a truly comprehensive description of the problem of FAS, which challenged me to think about how to broaden the perspective here in Michigan. The program here largely falls to efforts of a passionate few-- a noble effort, that has produced a very successful product. However, many of the disciplines and agencies that need to be involved at the state level are not visible and coordination of strategies is lacking. The federal Interagency Coordinating Committee on FAS (ICCFAS) could provide a template for Michigan on the types of membership needed to effectively meet the diverse needs of families with an FAS child or adult.

The ICCFAS is hosted by the National Institute on Alcohol Abuse and Alcoholism. Current membership includes representatives from various federal

(Continued on page 4)

International FAS Day



Humankind has not
woven the web of life.
We are but one thread within it.
Whatever we do to the web,
we do to ourselves.
All things are bound together.
All things connect.
~Chief Seattle~

September 9th has been declared INTERNATIONAL FETAL ALCOHOL SYNDROME (FAS) AWARENESS DAY. Everyone participating in FAS Day is invited to share in the "minute of reflection" at 9:09 a.m. on September 9th as a crucial message goes around the world. In this moment, the ninth minute of the ninth hour of the ninth day of the ninth month, we want to get out the message that in the nine months of pregnancy, women should not drink alcohol. In this minute, we also want the world to remember the millions of people around the world living with alcohol related birth defects.

The very first International FAS Day took place on 9/9/99. It was started by a group called FASworld. This is an international alliance of parents and professionals who do not want to see any more children, teenagers and adults struggle with birth defects caused by prenatal exposure to alcohol. The group was co-founded by volunteers in Toronto, Canada, and Tucson, Arizona. The first recognition of FAS Day in 1999 began in Auckland, New Zealand, where "Minute of Reflection" bells rang at 9:09 a.m., at Mt. Albert Methodist church. Then it moved to Adelaide, Australia, and then to South Africa, where at 9:09 a.m., Cape Town volunteers gathered to hear the War Memorial Carillon (the same bells that rang when Nelson Mandela was released from prison). Volunteers in Italy, Germany and Sweden held events -- and then FAS Day crossed the Atlantic. Volunteers staged events and bells and carillons

rang across Canada and the U.S. The western-most activity was the community breakfast on the tiny island of Kitkatla, British Columbia, near the Queen Charlotte Islands, where the village bell rang at 9:09 a.m. followed by prayers in the native tongue by village elders. This event has grown annually, with more and more countries joining each year.

We are requesting FAS advocates in Michigan to remember to participate in this international effort again this year. You can pause at 9:09 a.m. on September 9th and reflect or ring a bell as a reminder of the innocence of children and as a warning for pregnant women not to drink alcohol. You might also want to consider a broader effort for your community. Your plans need not be big but it is important that something happen in each community and that we build momentum each year. There is a helpful website to get you started on your own 9/9/2003 plans. See <http://www.fasworld.com/day.ihtml>

Please read on and learn what has happened in Michigan on previous International FAS Days and to learn about our connection with FAS efforts in South Africa.



Don't Snicker at FAS

By Clelia Terzanghi

The Marquette-Alger Counties FAS Workgroup coordinated a creative and successful International FAS Day campaign last year. The Marquette-Alger group is a part of UP FAS Task Force. Due to the geographic enormity of Michigan's Upper Peninsula, the Task Force has divided into smaller work groups that typically cover one or two counties. This allows the workgroups to meet on a more frequent basis and then the entire Task Force convenes quarterly via videoconferencing.

Last year, members of the Marquette-Alger Counties FAS Workgroup developed an action plan for International FAS Day involving local middle and high schools. In early August, a letter was sent to each middle and high school principal. This letter provided background on FAS, International FAS Day and an invitation to participate in a brief public awareness campaign directed at students and staff in their school. For those principals opting to participate, the workgroup provided a script that would be read over the school's public announcement system, FAS posters for school bulletin boards and one Snickers (fun size) bar for each student and staff member. Each Snickers bar was pre-labeled with "Don't Snicker at FAS...This candy bar will last a minute but Fetal Alcohol Syndrome (FAS) lasts for a lifetime." The workgroup also offered to pre-bag the Snickers bars so that each classroom teacher would get one package that could easily be distributed to students. Six schools elected to participate in the event. As a result, the group reached over 3,000 students which is a significant accomplishment in this rural area.

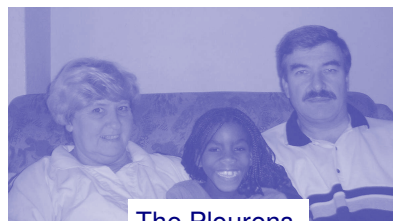
Additional action items in this campaign included issuing a press release ten days before the event; the press release mentioned the names of each participating school. Four days before the event posters, a script and Snickers bars were delivered. After the event thank you cards were sent to each principal and a letter was sent to the editor of the local paper which again mentioned the names of each participating school. Finally, certificates of appreciation were made for each participating school, organizations who donated materials for the event, and event supporters. Work group members personally delivered the certificates to the schools during their regular monthly meeting.

If you are interested in developing a similar campaign in your area, templates of materials used in this campaign are available by contacting Karen Twa, Fetal Alcohol Educator at Marquette General Hospital, phone 1-800-562-9753x7706 or email kltwa@mfire.com

BreakFAS—in South Africa

South Africa has the highest rate of FAS in the world. In Worcester, South Africa the rate is 52 times higher than the estimated rate in the United States. Nearly one in 15 children in this community has FAS. This shocking epidemic has captured the attention of the world.

In March, three pioneers from Michigan, Carolyn Morado, Mary Browning and Barbara Wybrecht, traveled to South Africa to learn more about the effects of FAS in this country. The experiences from their journey are difficult to articulate, but one thing they saw was that in spite of the overwhelming devastation caused by FAS, this is not a country without hope. One of the persons with whom the group met was Vivien Plourens and her husband Peter. They are adoptive parents of Tisha who has FAS.



The Plourens

The Plourens are the chairpersons for this year's FAS Day events in South Africa. Through education and advocacy, FAS Day events are now being sponsored by the national Department of Health. The FAS Day commemorations will involve a "BreakFAS" breakfast. One hundred people have been invited, including several high level government officials. They will have guest speakers and will distribute FASknots, each with a tiny bell in the middle. At precisely 9:09 a.m. Tisha will begin the ringing of the bells which will continue to spread the important message about FAS around the world.

FASD STATE SYSTEMS CONT...

agencies including:

- National Institutes of Health
- Agency for Health Care Research and Quality
- Centers for Disease Control and Prevention
- Health Resources and Services Administration
- Indian Health Service
- Department of Education's Office of Special Education and Rehabilitative Services
- Department of Justice's Office of Juvenile Justice and Delinquency Prevention

The ICCFAS's purpose is to exchange information, coordinate strategies, develop projects and promote collaboration in an effort to more effectively address

FAS on a national level. This process is similar to the work of Michigan's local community projects and is what is needed at a statewide level.

Though it would take more money than is currently available in Michigan to establish the infrastructure that has been developed in some states, we need to explore and incorporate these ideas as much as possible. Overall, the meeting was an excellent reminder of the reason for our efforts, a source of good strategies for success and an inspiration to press forward. I look forward to helping with realizing the goal of a more effective statewide system for FAS prevention and treatment.

Michigan FAS Web Newsletter
c/o Kent County Health Department
700 Fuller NE
Grand Rapids, MI 49503